

Project Purpose

Problem:

Developmental disabilities in children have a profound impact on families, school systems, communities and medical service delivery networks. Between 5% and 20% (depending on the level of severity under discussion) of children are affected by conditions that impact their physical, mental and emotional development. These disabilities include autism, mental retardation and cerebral palsy, as well as genetic and metabolic disorders. In New Hampshire, there are at least 15,000 children under the age of 18 who experience serious challenges to their health, development, learning, daily living, and eventual independence. These children require interventions from clinicians with specialized training to treat a variety of developmental issues. However, the limited number of physicians, therapists and other professionals with this expertise, and the isolated and rural composition of much of New Hampshire, inhibit the delivery of these needed services.

Primary care physicians, early intervention service providers, regular and special educators, childcare providers, and home healthcare providers need advice and training about healthcare, educational interventions, childcare and family support. As more children survive premature birth and other health challenges, and return to their families and communities with complex medical, developmental and educational needs, the capacity of families and communities to provide for, nourish, and sustain them comes under constant pressure. Community-based professionals, and the families and children they serve, need access to state-of-the-art evaluation and assessment.

New Hampshire's developmental pediatrics clinics have the capacity to provide between 600 and 1,000 visits per year. Most programs have a waiting period for appointments of between two and six months and can provide only minimal follow-up beyond the initial consultation. The current system of sending children and families to distant specialists does not allow the necessary follow-through and on-going communication which is required to support, adjust and fine tune treatment and recommendations. In addition, school systems often face special burdens – by law, they must provide an “appropriate education” but the schools often lack the staff and experience to accomplish this objective. As a result, community systems often fail to meet the needs of the children and families. Inevitably, poor outcomes such as reduced health status, reduced family functioning, sub-optimal educational outcomes, and expensive placements increase the burdens on community resources and leave families in distress.

Existing Model:

In 1995, Crotched Mountain developed the School Partnership Program (SPP) to provide assessment and evaluation services to school systems and healthcare organizations that serve children with special needs. Crotched Mountain has an experienced skill base of medical experts, therapists and educators. Through SPP, Crotched Mountain delivers comprehensive medical and educational evaluations for students with complex needs in community settings. These services provide valuable recommendations for the classroom environment, teaching techniques, learning styles, and, where appropriate, applications of assistive technology. SPP has provided over 500 evaluations of 200 children in communities throughout New Hampshire.

While SPP has increased the level of support available for many children, it is still insufficient to meet the demand for these services. In addition, the time required for SPP staff to travel to remote areas of the state limits the number of children who can be served. Many of these children require ongoing follow-up to monitor progress and refine recommendations, a service that is difficult to offer due to resource constraints.

Proposed Model:

In order to address these needs, Crotched Mountain will augment the School Partnership Program with a telemedicine and distance-learning project called SupportNet. SupportNet uses high-speed video-conferencing to allow more evaluations and follow-up of children with special needs, as well as special training to educators and healthcare providers. In order to reach the most underserved areas of the state, Crotched Mountain has a) join the Granite State Distance Learning Network (GSDLN) which allows access to over 24 communities; b) will add two additional sites to this network (one urban and one rural area) which will be dedicated to the advancement of this service model; and c) facilitate the diffusion of this model to other communities in New Hampshire.

Outcomes:

By using an existing educational network (GSDLN) to create interactive links between New Hampshire communities and specialists at CMRC, SupportNet will enhance the SPP in many ways:

- Assure ongoing evaluation, consultation, and assistance for children with disabilities, which will allow for modifications as they develop. The use of interactive television will allow Crotched Mountain to generate a continuous video record of a child's development, which may enhance future service provision.
- Increase by 50% the number of children served by the SPP from an average of 50 to 75 per year by the end of the grant period. This will also allow clinicians to reach children at earlier stages of development. Early intervention can have a critical impact on the outcome for children with disabilities.
- Enhance the knowledge and skills of community-based professionals and improve the care of an estimated 1,200 children with disabilities each year by delivering regularly scheduled workshops to multiple sites throughout New Hampshire.
- Demonstrate new benefits of network technologies and providing successful interventions, which can be diffused throughout New Hampshire and the nation.
- Reduce the isolation felt by children, families and locally based service providers.
- Create a community of users and generate opportunities for sharing ideas to serve children with disabilities and other populations in the state.
- Crotched Mountain will also use this capacity to serve the disability community through a variety of other programs. Please see (*Additional Benefits*) attached.

Innovation

Telemedicine is rapidly becoming an accepted means of providing health services in remote rural areas and in other special locations, such as overseas military bases and prisons. One study estimates that the current U.S. market for telemedicine will reach \$3 billion by the year 2002.¹ Telemedicine is used for consulting, video-conferencing, remote supervision, reaching underserved areas, and for the establishment of medical

¹ Business Communications Company, Telemedicine Opportunities for Medical and Electronic Providers, 1998.

records databases. The benefits of telemedicine include instant access to information, reduction of travel time for patients and doctors, research time and handling of paper records, as well as improved diagnosis and treatments.² Telemedicine is now the focus of national conferences, a national association and a journal that selects the top ten telemedicine programs each year.³

SupportNet employs network technology to reach underserved populations in both rural and urban areas through a distinct service model. TOP has funded a number of projects targeted to people with disabilities. Many of these have had the goal of promoting inclusion via technology or improving direct medical services through home monitoring. A few provide consultation and training for care staff, and many have had a geographic focus on rural and other isolated communities. The SupportNet project will advance the field in several ways:

- SupportNet will give priority to the diagnostic and assessment needs of children with complex disabilities. No other projects use networking technology to provide comprehensive diagnostic and assessment services for children with disabilities in their home communities.
- SupportNet provides a model of service that involves and benefits families, the educational system and medical providers.
- SupportNet's locus within the Crotched Mountain Rehabilitation Center provides unique access to multi-disciplinary therapeutic services and expertise while supporting a community-based approach.
- By equipping community agencies (early intervention, schools and home health agencies) with ATM video-conferencing access, SupportNet can foster communication among these entities resulting in improved communication and more coordinated services for children.
- Though telemedicine has been utilized for many years, extending this model to special education programs, early developmental services, and home health care providers has not been fully developed and realized.
- SupportNet brings the benefits of new technology to an underserved population - children with disabilities - particularly, those living in remote and rural areas.
- SupportNet adds a new dimension of service to an existing statewide network, which allows children with disabilities to benefit from the advantages of networking not only with Crotched Mountain, but also with an array of state, regional and national resources.

Diffusion Potential

More states are developing distance learning networks similar to New Hampshire's GSDLN which allow schools, colleges and universities to share resources and reach students over great distances. Many states including Missouri, Vermont and Iowa have well-developed distance learning networks which inter-connect nearly every community within the state. Other states have newer networks, which have grown quickly as programs are developed. SupportNet has tremendous diffusion potential because it combines the existing resources of a statewide educational network with those

² "Telemedicine Today," paper by Sandy Duncan, Duke University, 1999.

³ "Top 10 telemedicine programs for 1999: Experience pays off," Telehealth Magazine (Nov. 1999).

of a major pediatric medical center to serve smaller, locally based agencies, who otherwise would not be able to afford such technology.

The need for these services exists in most regions of the country. Similar programs could be developed to enhance the lives of millions of Americans with disabilities. Our plan calls for widespread dissemination of the results of this project to service delivery agencies and disability communities in New Hampshire and throughout the country. These points are elaborated below.

The Problem. SupportNet addresses a common problem throughout the country, particularly in states with fewer metropolitan centers, many small cities, large rural areas, and inadequate transportation networks. Often the only centers of expertise with the ability to assess children with disabilities or developmental delays are located in university medical centers at a great distance from homes and communities.

This population is growing as children with birth defects and developmental disabilities are surviving in larger numbers due to advances in newborn and pediatric care. The de-institutionalization of children with profound disabilities and development of service models centered in communities have greatly increased the need for community-based service strategies. Though willing, many community agencies (schools, early intervention programs and home health agencies) are not prepared for this new challenge and are unsure of how and where to access technical assistance, in-service training, ongoing consultation, and other needed supports.

Innovation. Smaller agencies increasingly have access to new technologies, such as the Internet, which allow video-conferencing at lower speeds and may be sufficient for some follow-up person-to-person communication. Only high-speed video-conferencing will allow the full motion video necessary to conduct clinical evaluations of the type described in this proposal. Since high-speed video-conferencing is not financially viable for smaller, locally based agencies, we will create a direct partnership relationship with school districts and other member organizations. Through this method, we will be able to provide a consistently high level of service to a variety of community organizations.

Ease of Replication. We expect to be able to demonstrate the success of this model to other communities participating in the GSDDLN and to a broader audience including service providers in other states. The SupportNet project was designed specifically to be replicated in New Hampshire communities and throughout the United States wherever the resources of an education network and a medical center could be connected. It can be duplicated using ATM, ISDN, or other broadband technologies, which may be more readily available depending upon location. The SupportNet model could also be adapted to serve adult populations including the elderly and those receiving hospice or mental health services.

Dissemination Plans. SupportNet has a specific focus on dissemination of the lessons learned to help sustain a program with school districts so that other communities might benefit. Dissemination activities are targeted to multiple audiences. These include academic audiences who document and compare best practices; the community of service providers to people with disabilities who continuously seek new means of improving services to their constituencies; and to families who want to provide the best possible care for their loved ones.

For academic audiences we plan to prepare articles for trade and academic journals such as *Telehealth Magazine* and the *Journal of Ambulatory Pediatrics* that

describe the implementation experience of the SupportNet project. Carl Cooley, M.D., the principal investigator, has authored many articles for medical journals addressing diagnostic and service strategies for children with disabilities. Dr. Cooley also plans to present our findings and recommendations at conferences for professionals concerned with technology solutions and telemedicine. Nancy Cook Smith, Ph.D., evaluation consultant, will also present findings at the American Educational Research Association's national conference.

For the parent community, we plan to submit articles to magazines such as *Exceptional Parent*, which are targeted to consumers and families. Crotched Mountain will also host a conference for practitioners from the community health, education and disability service organizations in New England at our conference center in Greenfield, NH. We have hosted many such events on topics related to services for people with disabilities. We will feature the SupportNet project lessons in our in-house journal that has a circulation of over 7,000, as well as on our web site.

Crotched Mountain is a member of several organizations representing healthcare and educational service providers including: the American Hospital Association, the National Association of Independent Schools, the American Health Care Association, the National Association of Private Schools for Exceptional Children, and the Society for Developmental and Behavioral Pediatrics. We will seek to present project findings at the national conferences of these organizations as well as the Christa McAuliffe Technology Conference, which attracts educators from across New England.

Project Feasibility

Crotched Mountain has been developing SupportNet for the past two years. With the help of a private grant, we have been able to examine equipment and connection options and select the most appropriate for this project, create the network infrastructure at Crotched Mountain, develop relationships with community partners at the local level, and assist the GSDLN in building a coalition of organizations to promote technology and distance learning services. Federal funding from TOP will allow us to enter a project implementation phase, connect new sites, and begin delivering these needed services.

Crotched Mountain participates in the GSDLN through a partnership agreement between Verizon (formerly Bell Atlantic) and the University of New Hampshire, which provides 1.5 Mbps for each site of which 768K can be used for interactive video-conferencing. Crotched Mountain has a Zydacron system with a 38" video monitor, which will enable our staff to fully evaluate a child's movement, behavior and condition. Each site brought on by Crotched Mountain will be capable of video-conferencing of speeds up to 768K and will be equipped with a Zydacron system with 34" monitor and remote controlled camera designed to be less intrusive in the evaluation environment for the student. We also have a newly renovated conference center equipped with a 180" screen and front-end projection system, which will allow conferences to be broadcast throughout the state and region. (*Please see the Budget Narrative for specific equipment list.*)

ATM service through the GSDLN was selected because of its availability to all of our community partners, cost effectiveness, and guarantee of constant bandwidth. The GSDLN features a "gateway" which allows broadband video-conferencing with organizations outside of the network as well. (*Please see attached Selection Criteria and Alternatives and SupportNet Diagram and GSDLN Map for more information*). Monthly

service agreements with UNH Telecom will supply the same 768K over T-1 lines for video-conferencing in Kearsarge and Nashua.

Crotched Mountain is particularly well suited to coordinate this planning effort because of our longstanding relationships with community-based professionals and expertise in serving individuals with disabilities throughout New Hampshire (*see attached Background.*) Crotched Mountain has undertaken a comprehensive redefinition of strategic goals in which short-term rehabilitation services, respite care supports, outpatient evaluation services, and expansion of community capacity to serve children and families are central themes. A planning partnership of the type described in this proposal would provide a timely and exciting opportunity to develop new collaborative relationships with other New Hampshire organizations with similar missions.

Leadership and coordination of this effort will be provided by W. Carl Cooley, M.D., Medical Director of the Crotched Mountain Rehabilitation Center and Adjunct Associate Professor of Pediatrics at the Dartmouth Medical School. Dr. Cooley has successful working relationships with all of the proposed community-based providers of health, educational, and developmental services. Dr. Cooley's research interests, for which he continues to have federal and state funding, include community-capacity building in the support of children with disabilities and their families, and the impact of managed care on services for children with special healthcare needs.

Technical supervision of the program will be provided by Jerry Hunter, Vice President for Information Services. Program evaluations, consultations and "in-service" training will be provided by Ludwig von Hahn, M.D. developmental pediatrician, and his multidisciplinary team of specialists in the School Partnership Program at Crotched Mountain. (*See attached biographical information on each SupportNet team member.*)

We will also be contracting with a faculty or staff member at each new site to help coordinate and promote this program in Kearsarge and Nashua. This helps ensure that equipment is used frequently for a variety of purposes outside the scope of the SPP program. Through ongoing curriculum sharing with other schools, special training programs for teachers, and other community services, the value of this technology will be more fully realized. This regular usage will lead to positive results and continued funding which is necessary to sustain the program beyond the grant period.

We are working closely with Dartmouth Hitchcock Medical Center (DHMC) in Lebanon, NH, which has been a leader in the field of telemedicine for many years. DHMC is providing both service models for this program as well as assistance in connecting Crotched Mountain to other physicians and specialists.

Community Involvement

SupportNet involves community partners ranging from New Hampshire colleges, universities, medical centers, and school districts to smaller, locally based early intervention programs, home health agencies and visiting nurse associations. On June 20, 2000, Crotched Mountain hosted a meeting with special educators from several school districts to discuss how this technology could be used to serve the needs of children with disabilities. From this and follow-up meetings, Crotched Mountain has designed a program which can be adjusted to serve the needs of individual schools.

In addition, Crotched Mountain has been involved in the creation of a special consortium to help extend distance learning to other New Hampshire residents. Through this consortium, Crotched Mountain has represented the needs of people with disabilities

and developed new relationships with network members. Crotched Mountain is also a member of the GSDLN coordinating committee, which is working to diversify educational programming and plan for the future growth of the network.

In Kearsarge and Nashua, we have identified three partners representing the local school district, the early intervention program serving infants and toddlers with disabilities, and the local home health agency or visiting nurse association which provides home supports to families of children with complex health and behavioral needs. These partners will have access to Crotched Mountain through a video-conferencing connection within the school district. Crotched Mountain has well-established working relationships with these partners: with the school districts' special education programs through the School Partnership Program; with early intervention programs through Dr. Cooley's work in the New Hampshire Child Development Services Network; and technical assistance and training program for early childhood professionals, the ADaPT project (*see supporting documents for Abstract*).

The appendices to this narrative contain letters of commitment from selected community partners, which describe the nature of these relationships and the plan for ongoing dialogue and evaluations using SupportNet (*see SupportNet Project Timetable for description of key events past and future*). The role of the SupportNet staff is to: a) provide Kearsarge and Nashua with the hardware, software, network connections, and staff training to establish an on-going link with the School Partnership Program staff and other resources at Crotched Mountain and b) coordinate the delivery of SPP service to these and other school districts on GSDLN. In exchange, school districts and community partners will ensure that appropriate staff is available for tele-consultations and training sessions, provide representation to the project planning and advisory committee, and assist with the evaluation process. (*Please see Community Partners for a complete description of each agency and their involvement in the program.*)

Privacy Statement

ATM offers a secure and direct connection between the UNH bridge and each site unlike standard IP, which runs over an open network. While UNH Telecom operates the bridge, they are not able to see the content of, or participate in any video-conferencing. Crotched Mountain has extensive experience complying with regulatory systems to ensure privacy. This rigor in storage and distribution procedures will continue in SupportNet for all paper and electronic documentation. SupportNet will provide private space for consultation, passwords, and network authorization codes for all users, documentation of all videotaped sessions, and security training for all community partners. The informed consent and/or direct involvement of parents will be obtained whenever consultation about individual children is provided and will comply with HIPPA guidelines, as they become final regulations with which healthcare institutions must comply.

Evaluation

TRIERY Research of Deerfield, NH, will serve as the external independent evaluator for the SupportNet project. This evaluation will include both formative and summative approaches. As CMRC and its partners initiate and develop the project, the formative data will facilitate building (and refining) a program that is well aligned with clients' characteristics and needs and will lead to continuing success after the grant is completed.

Summative evaluation data will focus on the degree to which project's clients are receiving improved services and therefore an enhanced quality of life.

The design of the evaluation will encompass the wide-reaching scope of the project through quantitative approaches, including collection of survey/questionnaire data from a variety of stakeholder groups. "Blind" client data (not identifiable by individual) provided by SupportNet professionals will also be analyzed to ascertain the impact of the improved services provided by SupportNet. The quantitative evaluation will be complemented and enriched by qualitative evaluation approaches, including in-depth interviews and journaling. Through this mixed method approach, the evaluation will seek to monitor the on-going operation to improve and identify the impact of the project on partner organizations, professionals serving the clients and the clients themselves. It will reveal if the SupportNet project is effectively reducing isolation, what ways video-conferencing has enhanced the lives of children and families, and what barriers exist in extending this technology in new communities for this and other populations.

Developing project specific instruments, including questionnaires and interview protocols, will be a first priority. These questionnaires will include parallel (but appropriate worded) items for targeted groups including CM staff involved with Support Net, staff in partner sites and clients' parents or other family members. All data collected through these surveys will either be anonymous or the identities of respondents will be held completely confidential by the evaluation staff. The questionnaires will be delivered both through Web-based survey forms and as paper and pencil forms with self-addressed stamped envelopes sent to TRIERE. Key individuals from each stakeholder group will be asked for interviews by evaluation staff. Although these interviews cannot be anonymous, the interviewer will not disclose individual interviewees' responses to others, including the evaluation staff. The interviews will probe for the reasons that might account for variations in survey data, the complexity of the service delivery, positive and negative aspects of the technological base, and perceptions of the project's impact. The interviewer(s) will be trained and the interview protocol will include probes for specific concerns. (*See attached Evaluation Plan for specific actions*)

Appropriate statistical and inductive qualitative data analytic techniques will be used to share the results of the evaluation. The Statistical Package for the Social Sciences (SPSS) will be used for inferential statistics, such as comparisons of different groups' perceptions and correlations between specific perceptions (e.g., quality of service delivery or impact on clients). The interview data will be initially analyzed separately, through approaches such as that of Miles and Huberman (1997). In the yearly reports the two analyses will be compared and contrasted for both similarities and differences. Thus, the evaluation will provide a rich understanding of both the on-going operations of the project and its ultimate outcomes.

This comprehensive and in-depth evaluation will facilitate the national dissemination of this project as Crotched Mountain working in other states may employ NH data as comparison standards. Moreover, we seek to improve the services delivered to New Hampshire communities in order to enhance the quality of life enjoyed by children with special medical needs.